



We believe that clinical practice is improved by patients being **partners** with clinicians and healthcare professionals, rather than passive recipients of healthcare

www.independentcancerpatientsvoice.org.uk



Independent Cancer Patients' Voice

- Patient advocate group run and lead by patients
- **Aim** - to bring the patients' voice to the cancer research community
- Members involved in clinical research
 - eg BCC Tissue Bank and Clinical Trials
- Study days inform members and consider clinical research
 - eg DCIS trial, essential oils, consent, statistics
- Active Google group and web site

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Current NHS Mantra

“No Decision About Me – Without Me”

- Different interpretations in practice
- Rarely actually hearing Patients’ voice
- Not necessarily what patients want
- How relate to MDTs?



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How relate to MDTs?

MDTs **crucial** to improved outcomes for cancer patients
MDT coordinators **essential** to successful MDTs

- Researcher View:
 - MDTs - largest contribution to better cancer treatments
 - most significant factor in improved outcomes of treatment
- Patient View:
 - Whole team working together
 - Best package of treatment of my tumour
 - Care for me as an individual
 - More aware of MDT giving increased confidence

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No Decision About Me – Without Me

- Should patients attend their own MDT discussion?
 - Already have right to see case notes letter
 - Have right to attend MDT??
 - Personally – think not good idea
- Should Patients carers or NOK attend MDT?
 - Huge responsibility for carer – not all could cope
 - May have difficulty feeding back to patient
- Should a Lay rep attend MTD meetings?
 - Too much for one person to do regularly
 - Maybe trained panel of lay people
 - Would need time with patients
 - Need proper supervision and funding

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The logo for Independent Cancer Patients' Voice features the words "independent cancer patients' voice" in a sans-serif font. "independent" is in blue, "cancer patients'" is in purple, and "voice" is in a larger, bold purple font. A blue brushstroke underline is beneath "voice".
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No Decision About Me – Without Me

- Patients were people before patients
- Different work & life experiences
 - Ages, cultures, family support, financial needs
- MDTs need to see Patient not just Tumour
- Many patients happy CNS is their Advocate

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Thank you



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